



Proclamation

Presented to

U.S. Hereditary Angioedema Association (HAEA)

Whereas, there are nearly 7,000 diseases and conditions considered rare (each affecting fewer than 200,000 Americans) in the United States; and

Whereas, while each of these diseases may affect small numbers of people, rare diseases as a whole affect almost 30 million Americans; and

Whereas, many rare diseases are serious and debilitating conditions that have a significant impact on the lives of those affected, their families, and caregivers; and

Whereas, according to the Food and Drug Administration, approximately 340 orphan drugs and biologics have been approved for the treatment of rare diseases affecting between 11 and 14 million people, but well over 15 million Americans suffer from rare diseases and have no treatment specific to their disease; and

Whereas, individuals and families affected by rare diseases often experience problems such as a sense of isolation, difficulty in obtaining an accurate and timely diagnosis, few treatment options, and problems related to accessing or being reimbursed for treatment; and

Whereas, many rare diseases such as hereditary **angioedema** and **mastocytosis** are relatively unknown by the general public, patients and their families bear a large share of the burden for raising funds for research, education, and awareness outreach; and

Whereas, thousands of Hawaiians and nearly one in ten Americans suffers from a rare disease; and

Whereas, the rare disease community organizes a nationwide observance of Rare Disease Day on the last day of February each year, and patients, medical professionals, researchers, and public and private entities involved in rare disease research join together to focus attention on rare diseases as a public health issue;

THEREFORE, I, NEIL ABERCROMBIE, Governor, and **I, BRIAN SCHATZ**, Lieutenant Governor of the State of Hawai'i, do hereby proclaim February 28, 2011, as

“Global Rare Disease Day”

DONE at the State Capitol, in the Executive Chambers, Honolulu, State of Hawai'i, this twenty-second day of February 2011.

NEIL ABERCROMBIE
Governor, State of Hawai'i

BRIAN SCHATZ
Lt. Governor, State of Hawai'i

